

# Status Report

THE NEWSLETTER OF THE PREMIER'S COUNCIL ON THE STATUS OF PERSONS WITH DISABILITIES

MAY 1998



## Employment

### CCRW Passes Knowledge to Community Agencies

**F**or over ten years, the Canadian Council on Rehabilitation and Work (CCRW) has been operating its Skills Training Partnership programs—STPs for short.

These groundbreaking initiatives have seen CCRW team up with business partners and community agencies to provide employment opportunities for Canadians with disabilities in such sectors as banking, information technology and customer serv-

ice. The process involves classroom and on-the-job training, with the outcome often being permanent employment.

CCRW has now committed to passing along its knowledge in this area to community agencies across Canada. With funding supplied by Human Resources Development Canada's Opportunities Fund, CCRW has implemented the Skills Training Partnership Orientation Program. The program will see CCRW train up to 50 agencies over the

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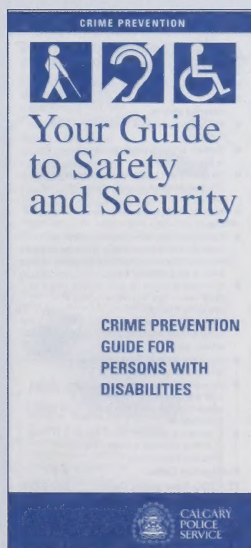
#### Brochure Focuses on Crime Prevention

**T**he Calgary Police Service has published a brochure dealing with safety, security and crime prevention for people with disabilities.

The brochure was developed with input and assistance from the Independent Living Resource Centre of Calgary. "The document has received recognition as the first significant crime prevention brochure for people with disabilities produced in conjunction with a police service in Canada," reports the Centre's Mark Iantkow. He adds that Alberta Justice has expressed interest in the brochure, which could result in provincial distribution.

In addition to producing the brochure, the Calgary Police Service's Crime Prevention Unit is planning to develop a permanent advisory council of knowledgeable consumers with disabilities.

For more information or to obtain a copy of the brochure, contact the Calgary Police Service at its non-emergency line, 266-1234, or the Crime Prevention Unit at 268-8399. ♦



course of the next two years, beginning with agencies in Manitoba and New Brunswick.

Participating agencies will be instructed in the development of STP-type programs, finding funds to manage the programs, and evaluating the success rate. Following the workshops, agencies that decide to create local STPs will be given a year of support and consultation from CCRW.

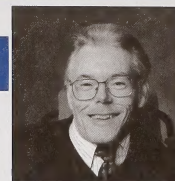
The result of the program is expected to be an enhanced ability among Canadian disability organizations to help clients find meaningful, permanent employment through partnerships. It's also expected to yield a minimum of eight new STPs in the next two years, resulting in permanent jobs for at least 120 people with disabilities.

CCRW has also launched a new one-day workshop entitled FIT-TO-WORK. The workshop can be delivered with a focus on either return-to-work processes for injured workers or hiring people with disabilities.

The goal is to provide organizations or companies with the tips, tools and techniques needed to effectively create return-to-work programs and ensure the successful employment of people with disabilities.

For more information on these and other CCRW initiatives, contact Amy Pike at CCRW by phone (416/974-2461) or by e-mail (info@ccrw.org). ♦





➤ Gary McPherson

# Improving Home Care Should Be Priority One

**I**n the modern world of health and medicine, home care isn't that exciting. From a pure publicity standpoint, it often takes a back seat to the latest medical technology or treatment. But it shouldn't. Properly orchestrated throughout our country, home care has the potential to be the saviour of our health care system, and it should be *the* top priority.

I use the term home care to refer to any type of service—including that provided by a family member—that allows a person with a permanent disability to live in their own home and participate in their community or a person with a temporary medical condition to recover in their own home.

Home care works. For those convalescing, there are holistic and economic benefits. For those with chronic conditions, it is the clear choice over institutional living, providing meaning to recipients' lives and reduced costs. The benefits are unarguable.

What is the state of home care in Canada? An excellent summary is provided by Phil Gaudet, President of the Canadian Home Care Association (CHCA), a national membership organization representing individuals and organizations with a stake in home care—a sort of united voice and access point for information and knowledge about home care and community support. Gaudet, who is also President of Edmonton-based Good Samaritan Society, recently attended a national conference on home care. In a CHCA press release, Gaudet said this about the conference and home care:

*"There is obvious consensus among the people here, and the general public, that investing in home care would strengthen our Medicare system and therefore it is a wise priority at this time. We are encouraged because we heard a very clear federal government commitment to this and we fully expect it will be backed up by dollars as soon as they are available."*

*"A significant investment in home care needs to occur. Some immediate funding is required to ease the stress points that are building. Current resources for home care services are not always meeting the increasing demand. Caregivers need assistance with the growing burdens in the home and they can't wait 18 months until we develop all aspects of a national home care strategy."*

*"In the longer term, we need to invest in information systems and research to determine how home care best supports a modernized health care system, and how home care can enable the system to be more flexible, more effective, and more client-focused."*

What Gaudet is saying, in essence, is that the outlook for home care is uncertain. While the public—and governments—acknowledge its worth and importance, the fact remains that our present home care system is under considerable stress and needs help now. But infusions of money aren't enough—the entire system of home care must be transformed to meet long-term needs. And when you consider that the so-called "grey wave" of seniors has yet to arrive, long-term needs are going to place considerably more strain.

From my positions of Chair of this Council and a long-time consumer of home care services, I couldn't agree more with Gaudet's assessment. And so I urge anyone who could affect the ultimate shape of Canadian home care to consider the necessity of providing support now and committing to long term planning.

What should the future of home care look like? I envision a system that is responsive to people's needs—but also one that encourages individual responsibility and as much independence as possible. I envision a system that is portable: in other words, consistent across our entire country, from province to province and region to region.

And I envision a system that is fair and equitable—one that acknowledges that those with disabilities are just as important as those with temporary medical needs. Such a system would recognize that the needs of the former aren't necessarily "medical" in nature and would understand the absolute importance of investing in people with disabilities in order for them to participate and contribute fully.

In short, I see a system of professional support, with a central focus of quality of life, that can be depended on when a disability, temporary or permanent, arises.

How our system of home care can reach this level is up to our politicians, administrators, experts such as Gaudet and CHCA, and others in positions of influence. But there appear to be two major stumbling blocks that need to be addressed. One is lack of funding for both immediate crisis control and long-term planning. The other is a lack of innovation—creative long term planning that takes into account the impact of home care in other areas such as transportation and housing.

Ultimately, funding is all about priorities and the will to act. I remain hopeful that, with enough informed debate and pressure provided by groups such as CHCA, home care will become *the* priority.

In contrast, developing creative new approaches will be a more difficult task. Further tinkering from a medical perspective will only result in incremental change—not the transformation that's required.

Consider this huge problem: agencies are having great difficulty recruiting, training and retaining qualified personnel. To some extent, staffing problems can be dealt with by increasing funding. But more innovative solutions must be developed. I've spent some time on this issue, and I believe the problem comes down to an inability to channel young people into the helping profes-



sions. Why not follow the lead taken by many organizations that strongly encourage young people to participate in a structured, internship program?

Such a program could use a basic standards training course. For some it would result in the beginning of a career in the home care field. For others, it could lead to other opportunities in health sciences. For others, it could simply provide meaning and purpose in their lives. It would allow new entrants into the workforce an opportunity to gain meaningful work experience while building a useful resume. It would potentially engender empathy, understanding and caring in our society.

It's just one idea. But solutions such as this could potentially help address the national home care needs. Innovative solutions are required along with commitment and will to act. The dialogue must now begin in earnest, and fresh minds must be brought into the discussion.

If you're reading this, and you're a politician, RHA board member, government program manager, hospital administrator, doctor, or, most importantly, someone with a fresh perspective on the subject, get involved. Your commitment to home care will yield a greater good for our entire health care system miles down the road. ♦

## Status Report

Editor: Cliff Bridges

*Status Report* is published quarterly by the Premier's Council on the Status of Persons with Disabilities and is intended to provoke discussion of issues concerning persons with disabilities. **This publication is also available on audio cassette** by contacting our office at:

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## Letters to the Editor

**I** am writing in response to an article in the February issue of *Status Report* (Federal Task Force Report Forgotten?), questioning the government's response to *The Will to Act*. This disability report is the product of a federal task force that involved people with disabilities from the outset; and it does set an agenda for the next millennium. It was led by the Honourable Andy Scott, whose commitment and enthusiasm for the issues at hand continue to be infectious and insightful. The report is not forgotten.

Andy Scott and his team reflect public service attitudes that value democratic development and responsible citizenship. Their approach is honest, non-partisan and truly collaborative. Their report challenges all Canadians—quite naturally including citizens with disabilities—to work together to build on their record of success and make our communities models of equality and dignity for all.

With respect, the Canadian attitude about disability has progressed "from paternalism to partnership" in addressing a disability agenda. As Prime Minister Jean Chretien said at a recent gathering in New York:

*"As we look to the past, we can savour the many the achievements we have made as a nation to enable Canadians with disabilities to play a fuller role in our society. As we look to the future, it is with the knowledge that the full inclusion of Canadians with disabilities is a work in progress."*

Federal Task Force Report Forgotten? Not from my perspective.

**David Kilgour**  
Minister, Department of Foreign  
Affairs and International Trade  
Government of Canada

**I** just read your article in the latest issue of *Status Report*. While you mentioned guide dogs for the blind (Seeing Eye Dogs) you forgot about Hearing Ear Dogs for deaf and hard of hearing people and Special Skills Dogs for the physically disabled.

All three types of dogs are trained by the Lions' Foundation of Canada in Oakville, Ontario. These dogs are given free of charge to qualified applicants. Applicants travel to Oakville to train on site for two weeks with the dogs.

I have a Hearing Ear Dog because I am hard of hearing. I have had my dog for over two years. We live in Bonnyville, Alberta, about a three hour drive north-east of Edmonton.

Others may call him a mutt, but Grinch is top of the line in my eyes. Grinch is a terrier sheltie cross, almost four years old and a very friendly and lovable pooch. Many people do not even know that this type of a guide dog exists and that they can help deaf or hard of hearing people cope with many daily situations that people with more hearing take for granted.

Five years ago, when I lost more of my hearing, I found that often I could not hear the phone, doorbell, alarm clock or stove timer. I became afraid that, while my husband was working, I would not hear the fire alarm, someone breaking into the house or one of my children sleeping or up getting sick. All this, compounded by the limitation or unreliability of hearing devices, made me decide to obtain a dog. As a mom with young school age children, assistance from a dog seemed more appropriate than having my children carry the responsibility of hearing for me.

I can appreciate some of the references made by Bill Owen about his dog Ansil. All guide dogs provide a great deal of independence to their owners, whether they are blind, deaf, hard of hearing or physically disabled.

If you would like more information, please feel free to contact me.

**Bonny Dolbec**  
403/826-1948  
4310 - 40 Street  
Bonnyville, AB T9N 1W1

*The Premier's Council welcomes letters to the editor, but reserves the right to edit for clarity and brevity. Send letters to the address shown at left.*





► Elaine Chapelle

## Council's Future Directions

**W**e are nearing the end of the Council's original ten-year term and looking forward to entering the beginning of its extended term (on July 1, 1998). Will the Council look the same as in the past? What will be its priorities? Here are some of the exciting things that are or will be happening.

**Council membership**—the Council membership will increase, likely to the maximum of 15 members permitted under the legislation. New members will be appointed, although current members may reapply. The call for nominations has yet to be announced, but if you or someone you know are interested, please send a resume to me and I will ensure that it gets into the right hands.

**Business Plan 1998 - 2001**—the Council's three-year business plan describes our mandate, mission, core businesses, achievements, opportunities and challenges. Major

areas in which we see opportunities and challenges for influence include:

- attitudes towards inclusion;
- policy shifts resulting from the 1997 Alberta Growth Summit;
- outcomes of continued devolution of government services and programs;
- information regarding services and programs available across the province;
- services and organizations of and for Aboriginal persons with disabilities;
- barrier-free, accessible transportation;
- affordable, accessible housing; and
- partnerships with government, community groups, service providers and others.

**Action 2000**—we are creating a new, updated tool to replace the 1990 *Action Plan*. Interestingly, but not surprisingly, many of the issues for action in 1990 continue to require attention as we move into the new millennium. However, the social, economic

and political landscapes in Alberta have shifted over the past decade, and strategies will need to be developed accordingly.

A plan for creating the new tool is being developed in conjunction with Council members. We expect the consultation process to be less laborious this time, as we will be able to use communication links developed over the last decade. New strategies will be developed keeping in mind the following participant comment to the Federal Task Force on Disability Issues, and reported in *Equal Citizenship for Canadians with Disabilities: The Will to Act* (p. 3): "Canadians with disabilities do not want any more papers to present, commissions to attend, or research to conduct. Canadians with disabilities want action under the thousands of pages of recommendations and creative solutions that have been tabled by a multitude of groups since 1981." ♦

### Alberta Committee, Metis Disability Group Celebrate Milestones

**T**he Alberta Committee for Citizens with Disabilities—ACCD for short—is celebrating its 25th anniversary.

ACCD's roots can be traced back to 1972, when members of the Edmonton Action Group and Lethbridge's Disabled on the Move collectively realized the need for a provincial voice from the perspective of disability. Throughout the years, the organization has gone through three name changes. But its focus has remained consistent, and it is recognized as one of our province's strongest voices for Albertans with disabilities.

Since its inception, ACCD has been a consumer-driven organization with representation from within the cross-disability community. ACCD's efforts during the evolution of disability-specific policy can still be felt today, as the organization helped develop the AISH and Aids to Daily Living programs and other government initiatives affecting Albertans with disabilities.

"ACCD has been an effective voice for people with disabilities in our province since inception," says Gary McPherson, Premier's Council Chair. "From modest beginnings, it evolved into a powerful advocacy group. I'm pleased to congratulate ACCD on 25 years of hard work, and I sincerely hope we'll see another 25."

ACCD can be reached by phone in Edmonton at 403/488-

9088 or by e-mail ([accd@oanet.com](mailto:accd@oanet.com)).

Meanwhile, the Metis Advocacy and Disability Society of Alberta—MADSA for short—recently celebrated its first year of successful operation. What makes the event so noteworthy is that the society has achieved this milestone with no paid staff, next to no funding, and little outside support.

"Within this past year, our organization has experienced positive growth, and from that growth, our dedication to meeting the needs of the Metis disabled has and will remain the same," reports MADSA president Brenda Giesbrecht. "We look forward to the year upcoming as we continue to make our collective voices as one and increase awareness of our presence in the Edmonton region and beyond."

MADSA is committed to a holistic approach in providing services, education and advocacy for Metis persons with disabilities, their families and their cultural way of life. Statistics Canada estimates that as many as 1/3 of all Metis people have a disability, and it's generally accepted that many Metis people fall through service delivery cracks because of their unique status.

For more information about MADSA, call 403/456-6844 or 403/463-6986. ♦





# Paralympics Book Educates, Inspires



ity perspective. There's also a section that provides an introduction to the various volunteers, professionals, advocates and athletes from around the globe that have been responsible for the Paralympics' growing success.

The book is clearly written and the photography and quality of printing and hard cover binding is superb. It's sure to offer inspiration to all and will become a definitive resource for professionals in the field of adapted physical activity.

Price for the book is \$26.95. It's available from the Alberta Northern Lights Wheelchair Basketball Society (403/433-4310). All proceeds from sales of the book will be used to further spinal cord research, rehabilitation, awareness and education through the Rick Hansen Centre at the University of Alberta.

-C.B.

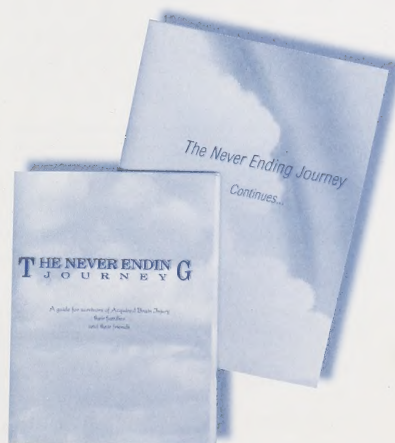
## Paralympics...Where Heroes Come

by Dr. Robert Steadward and Cynthia Peterson

*Paralympics...Where Heroes Come* is a full colour feast for the eyes that provides a comprehensive history of the Paralympics.

The book, authored by Dr. Robert Steadward, Director of the Rick Hansen Centre at the University of Alberta, and Cynthia Peterson, is the complete story of the Paralympic Movement from its early beginnings to the 1996 Summer Paralympic Games in Atlanta. Over 250 pages and 640 colour photographs chronicle the Paralympics from its humble beginnings to the elite sport performances of the modern day games.

One section provides an overview of the early days of wheelchair and disability sport, which was introduced largely as a form of rehabilitation treatment. Another section offers highlights from Paralympic Games of the last decade. A third section deals with the classification of athletes in the various events, as well as a look at the science of athletic performance from a unique disability perspective.



## The Never Ending Journey and The Never Ending Journey Continues

by Dayla Maisey

These two handbooks, written by Premier's Council Member Dayla Maisey, should be required reading for anyone dealing with the grief and emotional turmoil of brain injury.

ing with the grief and emotional turmoil of brain injury.

"There are various theories on grief," begins a passage in *The Never Ending Journey Continues*. "Many well-educated and intelligent people who work in the field of brain injury have created special models to explain the process and steps one is likely to take following a brain injury. I found frameworks helpful. However, I also found them to be somewhat constrictive. They were unable to encompass the broad spectrum of feelings and reactions I experienced."

In writing these two books, Maisey explains and expresses that "broad spectrum of feelings and reactions", mixing her recollections in eloquent prose with facts and coping strategies gleaned from other sources.

As a reader, you can't help but think that writing these books provided her with a way of expressing and dealing with her own grief and frustration (her brother sustained a brain injury in 1991). The result, however, is a startling honest account of her experiences and a rich resource of brain injury-related information.

Beneath the humble appearance of these books (they're self-published) lies a rare resource that may be the catalyst needed to begin the healing process for those dealing with this devastating disability.

Maisey has also completed a third book, *The Never Ending Journey Begins*, which is intended to be a standalone resource for families immediately following the injury of a family member (while in ICU).

Suggested donation for the two books described in this review is \$15 (includes mailing costs). The books will be provided at no cost to anyone who is unable to afford a donation. All proceeds will allow the author to continue her work in this area and help offset publishing costs.

Contact Dayla Maisey, P.O. Box 569, Okotoks, Alberta T0L 1T0, telephone: 403/691-2892, e-mail: dayla.maisey@shell.ca ♦

-C.B.





# Madenta On the Move

An Alberta firm is a world leader in assistive technology

► Cliff Bridges

**I**n less than a decade, Edmonton-based Madenta Communications Inc. has become a world leader in the area of computer access products and environmental controls for people with disabilities.

From its new headquarters on Calgary Trail, Madenta's 17 full-time employees develop, manufacture and market its groundbreaking products, which are sold through a network of some 75 dealers, primarily located in the U.S. Projected revenues for this year are as high as \$2 million, and a recent public offering on the Alberta Stock Exchange raised \$600,000.

How did Madenta achieve its growth and position? "As always, it's a combination of things," says Randy Marsden, Madenta founder and President. "First, we've learned how to market. Second, our tenacity and ability to survive in a tough market. Third, there are some very good people who work at Madenta. And fourth, we are innovative on both the product side and marketing efforts."

Had Marsden not met fellow Edmontonian Si Peterson, Madenta probably would never have gotten off the ground.

In 1987, Marsden was an electrical engineering student at the U of A when he met Peterson, a high level quadriplegic. As Marsden soon found out, Peterson was lively and passionate about life, but couldn't talk. And so Marsden decided to help his friend out.

As a school project, he designed an interface that allowed Peterson to write on a computer using a sip-and-puff headset. The same interface allowed Peterson to control lighting, stereo and several appliances. Marsden also built a voice synthesis system for Peterson that won second place in a national student engineering competition. Peterson revelled in his newfound communication abilities.

Marsden's work with his friend was the catalyst that changed his life. After graduating from the U of A in the following year, he founded Madenta and began refining the

technology—and developing new technologies—that would assist Peterson and others with similar disabilities.

Peterson died from pneumonia in 1993, but his memory continues to drive Marsden—and Madenta. "Very simply, I wouldn't be in this business had it not been for my relationship with Si. It was, and remains, a personal focal point for me."

One of Madenta's first products was Screen Doors, software that places a computer keyboard on the computer screen. Screen Doors allows full operation of the keyboard with any point and click device and provides computer access to those who can't use their hands. Today, the product has been greatly refined and is available for use with Windows and Mac platforms.

Another early Madenta product was PROXi, a box-like device that allows people with physical disabilities to gain sophisticated control over their environment. PROXi can allow control of 256 electrical items using simple voice command or keyboard interface. Telephone, lights, doors, audio/video and much more can be control-

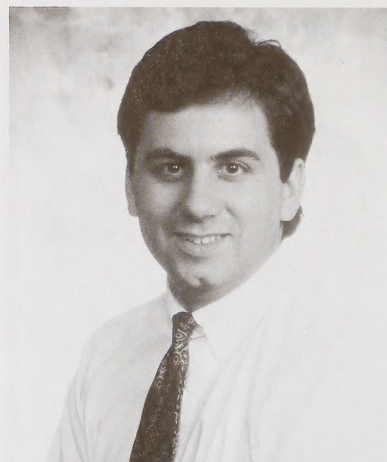
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**"Funding assistive technology is not only the right thing to do, it is also the financially responsible thing to do."**

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led with a voice command from virtually anywhere in the house.

More recently, Madenta developed the Tracker Hands-Free Mouse, which allows a user to control an on-screen cursor with head movements. The movements are read by an infrared light. Tracker can be used on virtually any computer—and on game machines such as Nintendo.



Randy Marsden, Madenta President

Early this January, Madenta continued its string of successes, announcing it had struck a deal with Microsoft. The deal allows Microsoft to package a scaled-back version of Screen Doors with future versions of the Windows operating system—and provides Madenta with considerable exposure to the world market.

Later that same month, Madenta struck another deal, this time with Tenax Software Engineering of Olympia, Washington. The deal gives Madenta distribution rights for Vortex, computer reading software for people who are visually impaired. Vortex should also prove to be useful for people with severe physical disabilities, in that it can offer relief of eye and neck strain.

With his newly bolstered product line, Marsden is bullish on Madenta's future. "We plan to be a \$5 million per year company by the year 2000," he says. "We plan to establish a distribution network in Europe and Asia. We plan to build a product in the future which integrates the four separate product categories of computer access, environmental control, augmentative communications, and powered mobility. It will be very cool. We plan to be the dominate company in assistive technology in five years."



He concedes the task is daunting. "It only feels rewarding when I stop and take a look back and see how far we've come. But when I look forward, all I feel is challenged. The peak is still much higher, no matter how far from base camp we've already come."

The biggest single challenge, he adds, is talking to people who need and want Madenta technology, but are unable to pay for it. "We have to fight constantly to make funders aware that our technology can actually save them money in the long run by providing independence, by promoting healthier lifestyles, and by getting people back to school and work. If I could only send out one message, it would be this: funding assistive technology is not only the right thing to do, it is also the financially responsible thing to do." ♦

*For more information about Madenta and its products, call 800/661-8406.*



One of Madenta's earliest successes was PROxi, an environmental control unit (left of computer). St. Albert's Darryl Park uses PROxi to control many of his home's appliances.

## Edmonton lacking accessibility, says Madenta President

**A**ccording to Randy Marsden, President of Madenta Inc., Edmonton fails the grade when it comes to accessibility.

Madenta recently brought its new regional sales manager for Texas, Hank Torres, to Edmonton for a week of training. The trouble began when Marsden called Yellow Cab to book a wheelchair accessible van to take Torres, a quadriplegic, to his room at the Fantasyland Hotel. Yellow Cab informed Marsden that it was impossible to book an accessible cab without 24 hours notice. There was no way they could free up a cab, and Torres was simply out of luck.

"I had images of Hank sleeping in our board room," says Randy. "I quickly went home, got my Safari Van, and took out the seats—it looked like it would do the trick. At the same time, someone from our office rushed to a local wheelchair sales company, and rented a couple of ramps that could be used to get wheelchairs up stairs."

But when they measured, they found that Torres' head would stick about six inches above the top of the roof of Marsden's van. "Unfortunately, the van didn't have a sun roof," says Marsden.

He quickly called Budget Rental Car and asked if they had a cargo van. The answer was yes. On the way to pick it up, he watched at a red light as a wheelchair-accessible Yellow Cab drove through the intersection. It was empty.

The van was secured, and Marsden attempted to install the ramps. But he had been given the 5-foot curb ramps, instead of 10-foot stair ramps. It took three men pushing Torres' wheelchair to make it up the 40 degree incline. On the way through the door, Torres' head hit on the latch and started to bleed.

The trip was safely completed (despite no tie-downs for the wheelchair) and Torres finally unloaded at Fantasyland Hotel

and said goodnight. But the saga was far from over, according to Marsden.

"As I picked him up the next day, Hank said, 'Randy, you've got to come up to my room and have a look at this.' What I saw was a 'wheelchair accessible room' that had the vanity in the bathroom nicely cut out so a wheelchair could pull under it. The only problem was the sink was about three feet over from the cut-out. It took Hank several maneuvers of his wheelchair just to get to the cut-out—kind of like parallel parking between two cars that barely have enough room between them for yours. In a word, it was inaccessible."

Marsden says that Torres' week in Edmonton continued with one mishap after another—incidents with handicapped parking, lack of curb cuts at busy crosswalks, and others.

"In the end," says Marsden, "Hank was very good-natured about it and said that it wasn't all that far out of the norm. I was completely embarrassed. We have taken Hank to many trade shows with us to Los Angeles, Minneapolis, Atlanta, etc. We never had a problem getting transportation or accommodation."

Marsden took the wheelchair ramps to the rental car company and showed them who made them and how to get a hold of them. "I explained that the ramp/cargo van combination seemed to be a viable option for wheelchair accessibility if they could provide a tie-down. They weren't interested."

He also later found out that Yellow Cab contracts their services to DATS (Disabled Adult Transportation System), which works on an appointment basis. "That's why they couldn't provide a cab—they were all booked up through DATS."

"In my opinion, Edmonton was out of the norm and a disgrace." ♦





# Murder Is Murder, Isn't It?

*Polite people don't talk about it anymore. Like politics and religion, there's a curious silence when it comes to discussing Latimer. The issue hasn't gone away. It still lurks disturbingly but the issue isn't resolvable and the risk of saying the wrong thing is too great. Murder is murder, isn't it? Yet...there are extenuating circumstances...why wasn't her pain looked after?...we don't let animals suffer...*

► **Audrey King**



**E**ven people with disabilities and their families can't agree on whether or not the minimal sentencing of Robert Latimer was justifiable. Those whose own lives seem hopeless support Latimer. Others, believing Tracy to be little more than a futureless pain-racked "vegetable", endorse euthanasia in this situation. Yet others, those with cerebral palsy, for example, who have lived through a childhood of assumptions related to worth and value, are terrified. The fear of living in a society which says it's okay to murder a disabled child but not a normal one is incomprehensible, unless you've been in Tracy's childhood shoes.

What's most to be feared about the Latimer story are the assumptions. Assumptions made about disabled persons' lives and the decisions arising, especially by persons in authority. Often seriously wrong assumptions are made, even by those who know us well.

A few weeks ago I was lunching at a nearby shopping centre with a friend. We were discussing Cher's speech at the recent funeral of Sonny Bono. This led to thought about our own funerals. I said, "I want a funeral which celebrates the wonder and fulfillment and uniqueness of my life. If anyone mentions courage, guts and tragic life stuff or says things like, 'she's free at last and rejoices in walking again,' I swear I'll come back to haunt them. I don't want people putting words to thoughts I've never had."

There was silence. She was stunned, unable to comprehend. Finally she replied, "You'd better write your own service then."

End of conversation, or so I thought. Imagine my surprise when, half an hour later in the middle of a bookstore, she suddenly said, "I'll speak at your funeral. If I'm still here. I'll read whatever you write, but then I'm going to say what needs to be said."

It was a shock to realize that her perception of my life didn't match my own. Severe childhood disability may have rendered me dependent on technology and human support, but I've never considered my life a tragedy, or felt useless, or courageous, or so full of pain and suffering I might sometimes wish to have ended it. Neither have I considered rejoicing in the potential miracle of a resurrected ambulatory body. Her assumptions were wrong. Whether I walk or not is as inconsequential to me as skiing might be to someone else. It's because of my childhood disability that my life has been, and continues to be, a uniquely rich journey of challenges, achievement, opportunities, friends, relationships and knowledge. I have a wisdom about life and humanity that's afforded to few. My quality of life is fine.

The notion that disability is a tragedy to be avoided at all costs is pervasive. In spite of the enormous, irreplaceable contributions of disabled composers, artists, politicians and scientists such as Beethoven, Van Gogh, Roosevelt and Stephen Hawking, throughout history society is constant in declaring that life with disability is costly and useless. We assume that life with disability cannot have any substance or quality. We continue to project the negative future of an unformed child from the deficiency we see before us.

It has been thus since earliest human history. The Bible, in Leviticus 21: 17-23, delineates the physical exclusions from the priesthood. Lepers are outcasts. Disability is retributive justice for offenses committed in a previous life. During the middle ages, persons were tortured and burned at the stake (e.g., Joan of Arc) for peculiarities not understood or accepted.

More recent history confronts us with the "purifying" atrocities of the Nazi regime. Today, supposedly benign prenatal screening technologies enable elective abortion of the imperfect before they arrive to trouble us. Is this so different?

Now, cloning for perfection offers to salve our conscience further by avoiding extermination of an imperfect fetus even before it occurs. How many human beings, both ordinary and exceptional, have we willfully eliminated? How many will we continue to do so?

Disability evokes assumptions of suffering, tragedy and pain. Perhaps our desperate need to eliminate it (and those who carry it) stems from its reminder of our own human frailty.

We try hard to prevent disability, to rid it from our midst, without regard to the natural order of things within a normal life span. We forget that accidents of birth or genetic aberrations are but a drop in the bucket compared to disability arising from trauma, disease and aging. Living involves loss and dependence. To be human is to suffer periodically throughout life, both physically and mentally. This is normal... for all of us.



In our quest to destroy disability, we too often also unwittingly destroy the soul and confidence of those with disability, especially children. Stamps on envelopes from a rehabilitation centre urging society to eliminate spina bifida through amniocentesis, or stamp out cerebral palsy, tell such children they are not wanted. Children are not born feeling inferior or deficient. They learn it—from us.

We fear dependence. We value self-reliance and honour those who grow up stand-

**“Society and history seem to insist on assuming the worst where disability is concerned.”**

ing on their own two feet. We reject our weaker citizens whom we assume will only take and bring us down by draining our resources.

Yet dependence is relative. The recent ice storms in Quebec and eastern Ontario were a savage reminder of the vulnerability we share in survival. Nature has a way of reminding us that we are all dependent and interdependent.

Tracy did not ask to die. She was not asked if she regarded her life as hopeless or lacking in pleasure. Indeed, her mother's diary and family photos suggest days of joy and happiness. The worth of her life was assumed by those who have not worn her shoes.

Terror and fear were struck in the hearts and minds of Canadians with disabilities when Robert Latimer murdered his disabled daughter in 1992. That terror has stayed alive throughout the disability network. Focus groups, support circles, e-mail, Internet chatlines, the *Latimer Watch* from the Council of Canadians with Disabilities in Winnipeg, memorial services, publications. The intensity of such activity across Canada underscores the vulnerability and grief arising from the shocking realization that persons with disabilities are viewed as dispensable.

Murder is murder, isn't it? Many outraged people would be satisfied if Robert Latimer had received the normally expected

sentence for second-degree murder. That would send a strong message for sure, but would it really alter the issue? Society and history seem to insist on assuming the worst where disability is concerned.

When I was a child, my mother and I were told of a lovely seaside home for children such as me. I was not allowed to go to a school for handicapped children because I was too disabled. I was discouraged from applying for a scholarship. A family doctor would not sign a university application form, and later, a university faculty's secret agreement to accept me on a trial basis ... never mind that I had been the top graduating student in an urban high school of 1,500 students. They were sure I would never get a job, so what was the point? In that final high school year, after years of being unrehabilitatable,” I overheard my orthopedic surgeon say to his colleague, “She's very bright. We should consider tendon transfers so she can use her hands better and stabilize her spine.” These are indelible memories.

Assumptions are at the heart of the Tracy Latimer story. Assumptions about the lives of people with disabilities. Arguments can be made for both sides, but the truth is, none of us really know what truly motivated her father or how Tracy felt. We can only make

assumptions based on our own life experiences, which we weigh against the evidence presented by the media.

Robert Latimer was a caring father, a kind man, a parent whose pain threshold finally drove him to commit a desperate act on behalf of his suffering child. That's what the media's representation of society's response seems to have largely concluded. But Robert Latimer is just one man. The bigger issue and the real terror lay in man's long history of rejection of, and discomfort with, disability. The precedent set by society and the justice system in assuming that Tracy's life was not worth living—to the extent that putting an end to it was, in the trial judge's words, a case of “compassionate homicide”—reinforces a cruel and dangerous stereotype.

I succeeded in spite of negative assumptions, lack of support and significant barriers erected by those whom society appoints to positions of authority and control. Tracy didn't succeed. She didn't get the chance to say her life was worth it. ♦

*Audrey King, a Toronto writer, has recently retired from the position of Client Advocate at the Bloorview MacMillan Centre. Reprinted from Rehabilitation Digest, March 1998.*

## CHRONOLOGY OF THE LATIMER CASE

### October 24, 1993

Tracy Latimer, age 12, died from carbon monoxide poisoning in her father's truck on the family's farm near Wilkie, Saskatchewan. Her father, Robert Latimer, first said she died in her sleep but later took responsibility for her death, claiming it was a mercy killing and that he could no longer watch her endure the pain and suffering associated with her disability (cerebral palsy) and associated medical and surgical treatment.

### November 16, 1994

Robert Latimer was convicted of second-degree murder. The conviction and mandatory life sentence with no chance of parole for 10 years was appealed and subsequently upheld by the Saskatchewan Court of Appeals. A new trial was ordered, however, after evidence surfaced of improper procedures with regard to the jury.

### November 5, 1997

A new jury convicted Robert Latimer of second-degree murder, but recommended to the judge that the mandatory sentence be waived and that he serve one year in jail before parole.

### December 1, 1997

The trial judge, Mr. Justice G. E. (Ted) Noble of The Court of Queen's Bench, ruled that the mandatory life sentence with no chance of parole for 10 years was too harsh under the circumstances. He found that Latimer's was a “rare act of homicide that was committed for caring and altruistic reasons” and sentenced Latimer to two years less a day, 12 months to be served as house arrest, on the family farm in Wilkie. ♦





# The Disability/Job Connection

**W**hat are the most common jobs people with disabilities find after vocational rehabilitation? What is the link between specific disabilities and specific jobs?

A recently completed U.S. study provides some answers to these questions. The study, carried out by West Virginia University's Richard T. Walls, professor and research director, and Steven L. Fullmer, research assistant professor, was reported in the September 1997 issue of the *Rehabilitation Counseling Bulletin*.

Using a 1992 database, the authors studied the case records of 103,417 people, all of whom found competitive employment after receiving vocational rehabilitation. These individuals represented 13 disability categories: visual impairment (7%), hearing impairment (10%), cerebral palsy (1%), arthritis (2%), spinal cord injury (4%), amputation (2%), mental illness (23%), developmental disabilities (16%), substance abuse (18%), learning disabilities (10%), diabetes (1%), epilepsy (2%), and heart disease (2%).

All records were analyzed on the basis of their disability codes and six digit Dictionary of Occupational Titles (DOT) codes, which allow accurate pinpointing of occupation and worker function ratings of tasks performed in the job (function in relation to data, people and things).

**Table 1** (right) shows the top jobs, ranked from 1 to 50, for all individuals, regardless of disability. In other words, janitors, chefs and cooks, and attendants are the top three occupational outcomes.

Means for employee relationships to data, people and things are illustrated in **Table 2** (below). These means are also defined by DOT: data ranges highest to lowest from 0 (synthesis of data) to 6 (comparing data); people ranges highest to lowest from 0 (mentoring) to 8 (taking instructions, helping people); things ranges highest to lowest from 0 (setting up things) to 7 (handling things).

Disability Category	Data	People	Things	Total
Visual Impairment	3.8	6.4	4.8	15.0
Hearing Impairment	4.0	6.6	4.5	15.1
Cerebral Palsy	3.9	6.4	5.1	15.4
Athritits/Rheumatism	3.5	6.2	4.6	14.3
Spinal Cord Injury	3.4	6.3	4.4	14.1
Amputation	3.7	6.5	4.3	14.6
Mental Illness	4.1	6.6	4.6	15.3
Developmental Disability	5.1	7.2	5.3	17.6
Substance Abuse	4.0	6.7	4.3	15.0
Learning Disability	4.5	6.9	4.8	16.2
Diabetes	3.5	6.2	4.6	14.3
Epilepsy	4.1	6.6	4.8	15.5
Heart Disease	3.6	6.4	4.4	14.4

Rank	Occupation	Frequency
1	Janitors	4940
2	Chefs, Cooks (Hotel and Restaurant)	4856
3	Attendants (Hospitals and Health)	4046
4	Porters and Cleaners	3613
5	Kitchen Workers	3605
6	Steno, Typing, Filing and Related	3551
7	Waiters, Waitresses and Related	3223
8	Miscellaneous Sales	3064
9	Cashiers and Tellers	2957
10	Miscellaneous Construction	2899
11	Packaging and Materials Handling	2627
12	Packaging	2552
13	Shipping, Receiving, and Stock Clerks	2202
14	Motor Vehicle Mechanic and Repair	1988
15	Household and Related	1959
16	Secretaries	1893
17	Medicines and Health	1667
18	Miscellaneous Structural Work	1657
19	Computing and Account Recording	1644
20	Typists	1616
21	Miscellaneous Personal Services	1495
22	Moving and Storing Materials and Products	1386
23	Security Guards and Correction Officers	1368
24	Carpenters	1315
25	Sales Clerks	1238
26	Sales Occupations (Miscellaneous Commodities)	1227
27	Lodging and Related	1184
28	Metal Unit Assemblers and Adjusters	1175
29	Truck Drivers (Heavy)	1135
30	Service Industry Managers	1101
31	Information and Reception Clerks	1097
32	Registered Nurses	1083
33	Plant Life and Related Service	1076
34	Computers and Peripheral Equipment	1051
35	Housecleaners (Hotel, Restaurant and Related)	1031
36	Social and Welfare Work	1025
37	Housekeepers (Hotels and Institutions)	984
38	Miscellaneous Cooks (Except Domestic)	977
39	Bookkeepers	975
40	Miscellaneous Managers and Officials	908
41	Sewing Machine Operators (Non-Garment)	899
42	Administrative Specializations	894
43	Preschool, Primary and Kindergarten Education	892
44	Unlicensed Birth Attendants and Practical Nurses	856
45	Miscellaneous Clerical	839
46	Gardening and Groundskeeping	834
47	Automotive Service and Parking	791
48	Accountants, Auditors, and Related	775
49	Accounting and Statistical Clerks	761
50	Passenger Transportation	727



Disability Category	Occupation 1	Occupation 2	Occupation 3	Occupation 4	Occupation 5
Visual Impairment	Household & Related	Attendants	Chefs & Cooks	Miscellaneous Sales	Janitors
Hearing Impairment	Steno, Typing, Filing	Janitors	Attendants	Chefs & Cooks	Typists
Cerebral Palsy	Steno, Typing, Filing	Miscellaneous Sales	Janitors	Kitchen Workers	Chefs & Cooks
Athritis/Rheumatism	Steno, Typing, Filing	Computing, Acct. Record	Cashiers & Tellers	Attendants	Secretaries
Spinal Cord Injury	Steno, Typing, Filing	Security Guards	Medicines & Health	Attendants	Motor Vehicle Mechanic
Amputation	Motor Vehicle Mechanic	Steno, Typing, Filing	Janitor	Attendants	Security Guards
Mental Illness	Janitors	Attendants	Chefs & Cooks	Steno, Typing, Filing	Porters & Cleaners
Developmental Disability	Kitchen Workers	Janitors	Chefs & Cooks	Porters & Cleaners	Packaging
Substance Abuse	Misc. Construction	Chefs & Cooks	Attendants	Waiters & Waitresses	Janitors
Learning Disability	Chefs & Cooks	Janitors	Attendants	Miscellaneous Sales	Packaging/Materials
Diabetes	Registered Nurses	Cashiers & Tellers	Attendants	Steno, Typing, Filing	Secretaries
Epilepsy	Janitors	Steno, Typing, Filing	Attendants	Porters & Cleaners	Chefs & Cooks
Heart Disease	Janitors	Attendants	Cashiers & Tellers	Steno, Typing, Filing	Sales Occupations

*Note that lower means indicates higher functioning.* For example, look at the "Data" column. With a mean rating of 3.4, people with spinal cord injuries have the highest functioning in their jobs in relation to working with data. People with developmental disabilities, with a mean rating of 5.1, have the lowest functioning in relation to working with data.

The most frequent occupations for the 13 disability categories are shown in **Table 3** (above).

In concluding the article, Walls and Fullmer point out that there is much similarity across disability categories in their types of employment, giving indirect evidence of the greater influence of functional abilities as opposed to disability category in job place-

ment. Thus, say the authors, vocational counsellors should focus on function: "Careful matching of a person's functional limitations with the requirements of the job should assist in training and placement decisions." ♦

*Reprinted from Stopwatch, October 1997, Canadian Association for Vocational Evaluation and Work Adjustment.*

## Federal Disability Policy Update

### CPP Modernizing Continues

The Canada Pension Plan's disability provisions continue to evolve. Beneficiaries can now take advantage of work incentives that will allow a return to school or volunteering without losing benefits. They can also continue to receive benefits for three months after returning to work and have their application fast-tracked if their disability again prevents them from working.

The program is naturally concerned that only those who require disability benefits receive them. As such, it has implemented new appeals and strengthened reassessment procedures.

As of January 1st, 1998, there are a number of some new rules regarding eligibility for and level of CPP disability benefits. For more information, contact CPP at 800/343-8282.

### Justice For All

Last October, Justice Minister Anne McLellan tabled several proposed changes with the goal of allowing people with disabilities to participate fully in the justice system.

Proposed amendments to the *Canadian Human Rights Act* add a "duty of accommodation" that would require employers to address the needs of people with disabilities.

Amendments to the *Canada Evidence Act* would provide for assistance for persons who have special communications needs. In addition, alternative methods for identifying the accused, such as auditory and tactile recognition, would be allowable.

Amendments to the *Criminal Code* would ensure that persons with disabilities can't be excluded from jury duty because of disability, allow persons with disabilities to provide testimony through videotape, and create a new provision establishing the offence of sexual exploitation against persons with disabilities.

For more information, contact Gloria Mintah at 613/941-1978.

### Access to Passenger Trains

Under the Canadian Transportation Agency's new Rail Code of Practice, all passenger trains were required to have at least one narrow wheelchair on board by April 1st of this year. And by April 1st, 2001, all passenger trains will be expected to provide a passenger car with at least one tie-down space that will accommodate a person in their own wheelchair, extra room for a service animal, and accessible washrooms.

Any new rail cars or those undergoing major refurbishing must meet the new accessibility code. Other requirements include providing food and beverage service for wheelchair users if they're unable to access dining cars, accepting service animals and mobility aids free of charge, and providing carrier assistance to board and disembark.

Like other CTA codes of practice, the Rail Code of Practice does not lay down legal requirements that force carriers to conform. The Code will be monitored to determine if the voluntary measures prove adequate. ♦



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## Recreation

# Edmonton's River Valley Accessible to All

**T**his summer, you can cruise the 130 kilometres of Edmonton's river valley park system in style.

Using a grant from the Alberta Sport, Recreation, Parks and Wildlife Foundation, the Canadian Paraplegic Association purchased an adapted cart for use in the Edmonton park system. The cart has been modified to allow easy transfer from a wheelchair to the cart seat. It also has an attachment on the back to carry a wheelchair.

Ownership has been transferred to Edmonton Parks and Recreation, which will operate the cart out of Rundle Park.

Meanwhile, a series of trail maps, which will include accessibility information for use by persons with disabilities, are being produced. Trail signage will also be improved to be useful for all park users. ♦



This accessible golf cart, purchased by CPA Alberta through a grant from the Alberta Government, is now available for wheelchair users to explore Edmonton's river valley.

## Coming Events

The Active Living Alliance for Canadians With A Disability presents Forum '98. May 13 to 16, 1998, in Victoria, B.C. Forum '98 will provide opportunities for professional development and educational/practical sessions for people involved in active living, including sport and recreation professionals, educators, government managers and consumer groups. Contact: Active Living Alliance for Canadians With A Disability at 800/771-0663 or by e-mail ([disability.alliance@rtm.activeliving.ca](mailto:disability.alliance@rtm.activeliving.ca)).

The Canadian Hard of Hearing Association (CHHA) Edmonton branch presents the CHHA Annual General Meeting and Conference. May 29 - 30, 1998, at the Fantasyland Hotel in Edmonton. Theme: A Sound Family. Various topics related to hard of hearing issues. Contact: Cindy Gordon at 403/492-7070 or by e-mail ([cgordon@planet.eon.net](mailto:cgordon@planet.eon.net)).

The B.C. Association for Community Living (BCACL) presents its Annual General Meeting and Conference. June 11 - 13, 1998, at the Grand Okanagan Hotel in Kelowna, B.C. Theme: acknowledging the proud history of the community living movement and future potential. Contact: BCACL at 250/875-1119.

The Health Law Institute, University of Alberta, presents the Second International Conference on DNA Sampling. September 10 - 13, 1998, at the Hotel MacDonald in Edmonton. Theme: The Commercialization of Genetic Research: Ethical, Legal and Policy Issues. Contact: Timothy Caulfield, Conference Chair, at 403/492-8358 or by e-mail ([tcaulfld@law.ualberta.ca](mailto:tcaulfld@law.ualberta.ca)). ♦

*Forward your conference information to us at the address shown on page 3.*

